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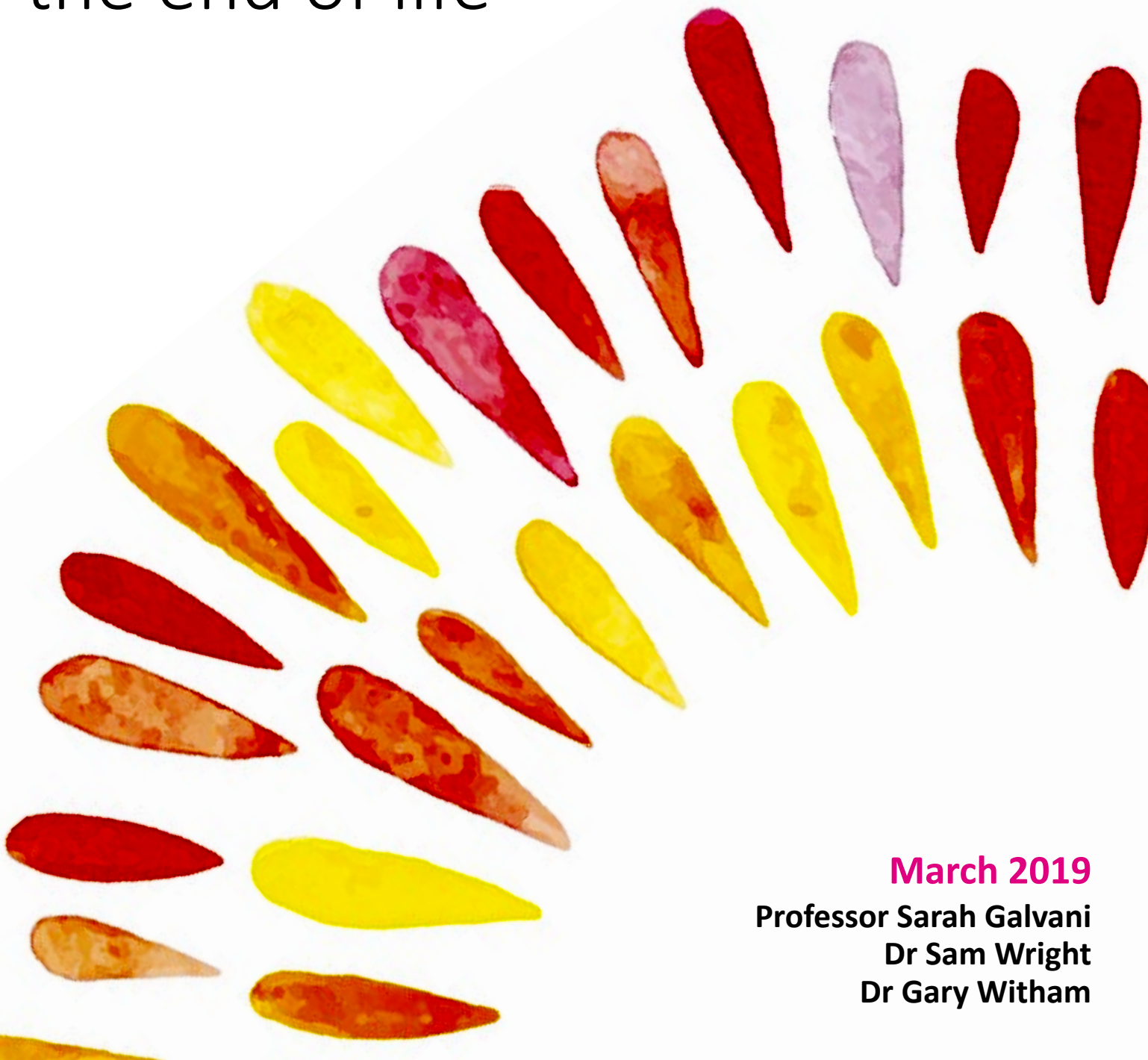
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Good Practice Guidance

Supporting people with
substance problems at
the end of life



March 2019

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Introduction

This good practice guidance draws from a range of sources including international research evidence, the experiences of people who use(d) substances who are at the end of their lives, and the family members, friends and carers of those people. It also draws on professionals' experiences including paid and volunteer professionals who work with people in a range of settings including hospices, community health and social care services, substance use services, as well as specialists leading work in this area within their own disciplines, for example, general practice medicine, hepatology, social work.

To our knowledge, it is the first guide of its kind in this newly developing field. Work has been developed by St Mungo's, Marie Curie and the Care Quality Commission (CQC) to examine the end of life care needs of other disadvantaged groups of people, for example, people who are homeless, people from BAME communities and LGBTQ+ groups. However, this is the only work to explore substance use directly and to consider the impacts that problematic substance use (past and present) has upon people's lives and those of their families, friends and carers. This guide attempts to bring perceived good practice to individuals living and dying with problematic substance use and to the professionals and families who support them. It is not exhaustive but offers some suggestions and areas for practice development and reflection.

The goal of palliative and end of life care is to give the person the best quality of life possible towards the end of their life, and to give them, and their family and friends, the best possible care experience of dying and death. The World Health Organization (WHO) defines palliative care as *'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual'*.

However, the problem for many people who use(d) substances and those caring for them is that their end of life is often only identified in the last few weeks or days of life. This means that, for both health and social care staff and family/friends, care planning and opportunities to talk meaningfully with the person approaching death may be extremely limited. Such conversations can be all the more difficult for families if relationships have become strained or fractured – which is where practitioners working within substance use services may be able to help.

Key messages

One of the key messages from practice with people at the end of their lives with current or historic problematic substance use is the **complexity and multiplicity** of their needs (see figure 1). This negatively impacts upon their engagement with services and the delivery of care. It is therefore important to **identify these needs early** and to have **local partnerships** and **joint working arrangements** in place to ensure these needs can be met. No single agency can be expected to meet them all.

To meet such needs **better training and education** on substance use and end of life care for applied professionals is required as well as **policy and practice** guidance and **post qualifying training** to support those already in the workforce. This training should extend to social care and other support workers (such as

staff in shelters), who may not be automatically considered, but are working in services where they are likely to be in contact with people with problematic substance use. The research suggests that **emotional support** for staff is important given that working with problematic substance use and/or end of life care can be emotionally labour intensive.

Other key messages include the need to review, or plan for, **family service provision**. More generally, **obstacles to accessing specialist palliative and end of life care services** inhibit the delivery of support to a more diverse population. For some populations, consideration has to be given to delivering end of life care in a **range of accommodation types**.



Figure 1: Complexity of needs

1. Philosophy of care and service approach.

People with problematic substance use (PSU) meet hostility, suspicion and frustration from a range of care professionals on a regular basis. It prevents service access and can lead to mutual suspicion and mistrust. Professionals need to counter stigma and stereotyping around people with PSU to regain this trust. A non-judgemental and empathetic approach is needed when working with people with PSU in palliative or end of life care, as is a commitment to providing the best care and treatment no matter what got them there.

Professionals advise that it can be helpful to:

1. Understand that PSU during palliative care (PC) or end of life care (EoLC) is possibly a coping mechanism at a difficult time in someone's life. More generally, PSU is a known coping strategy for people countering pain, trauma and distress.
2. Understand from the outset that there are likely to be unpredictable illness trajectories. PSU may also fluctuate – complicating identification of symptoms and how and when to respond.
3. Pre-plan care and consider how to manage the complexity in order to enable the provision of the best possible care – and ensure that any anxieties among staff are acknowledged and discussed.
4. Recognise that survival timescales may be much shorter and less predictable for people with PSU than for many other life-shortening conditions – so communication and planning may need to be very focused.
5. Avoid treating people with PSU as if they are undeserving – consider their PSU, and its consequences, as part of their medical condition or social needs.
6. People with PSU may not feel deserving of PC and EoLC. This needs to be countered with compassionate and joined up care. They may seem to be defensive and deny that they need help – and whilst it is important to respond to an individual's wishes, it may be more appropriate to explore with them what their previous experiences and current expectations of services are and how their engagement with services could best benefit them and their family or carers.
7. Harm reduction discussions around PSU are more appropriate than 'recovery' focussed interventions for this group of people. The aim is to keep people stable rather than pushing for other goals such as abstinence – unless the person wants to.
8. Consider whether waiting list times within substance use agencies can be speeded up if someone is in need of PC or EoLC. They may wish to spend their final days or weeks substance free to reengage with family, friends and carers.

Service models for people with PSU and in need of PC/EoLC

- People with PSU and professionals supporting them, talk highly of holistic models of care where more time can be spent with people. For example: alcohol teams that work with people on every aspect of their needs, not just the alcohol, accompanying them to appointments where possible. Hospice care is usually multi-faceted and geared towards supporting the person as they approach the end of their life.
- Ideally, a coordinated care model is needed, with a case manager or care worker to avoid people slipping through the gaps.
- Involving people with lived experience to participate meaningfully in designing, assessing, and evaluating services is important.

- At a minimum, close partnership working with other appropriate agencies is needed to support the individual and their family member.
 - Other options include dedicated specialist roles, services, and champions, funded from integrated or specialist commissioning, e.g. palliative care coordinator for homeless people, funding hospice beds in hostels.
 - Assertive outreach and engagement with, for example, people who have dropped out of care or people needing home visits.
5. Developing safety plans for people whose PSU is identified as high risk who have palliative/ EoLC needs.
 6. Developing organisational level policies that reflect an awareness of the overlap between PSU and PC and EoLC. One example would be substance use services including a regular self-audit of people attending the service using a tool such as SPICT or the Surprise Question (see resources section). Similarly, PC and EoLC services can review the case notes of people in their services for any indication of substance use and use the AUDIT questionnaire if they have concerns.

Services need to be:

1. As flexible and as accessible as possible, particularly around appointments.
2. Aiming for low threshold strategies to care, i.e. minimum restrictions on normal patterns of behaviour.
3. Delivering care in settings familiar to individuals, e.g. hostel-based care, home care, where possible.
4. Person-centred – building positive relationships, communicating well, providing personal care.
7. Providing and encouraging staff to participate in workforce development on SU or PC/EoLC.
8. Clear that managers must offer active support to staff to ensure their continued well-being while working with these more complex issues. This support must not be cut as services are squeezed financially. It may include allocating staff more time to work with people with PC/EoLC/PSU needs, particularly given the need for multi-disciplinary and multi-agency involvement.



2. Joint working

Without fail, a clear message for supporting this group of people was the need for joint working. Research shows that a number of strategies have been tried, or recommended, to effect such partnerships.

Strategies to effect joint working

1. Building closer working relationships with GPs who are a main contact for prescription management.
 2. Building good relationships with other specialist services – even just one lead from each service can keep communication channels open.
 3. Bringing experts in to team meetings to discuss particular issues around PC/EoLC and PSU, especially experts in asking about ‘sensitive’ issues.
 4. Establishing working relationships with other community agencies, e.g. pharmacists and district nurses, to support people in the community or if there are concerns over drug diversion at home.
 5. Offering training or guidance to other agencies – that is, not waiting for them to ask! This is particularly important in order to provide specialist advice, emotional and practical support, and clinical supervision to practitioners to counter the emotional demands of working with people who are dying.
- A palliative care consultant visited a hospital to speak to medical staff about the higher doses of medication required for patients with histories of, and tolerance to, opiates.
 - Moving a person from the use of Novel Psychoactive Substances (NPS) to a pain patch to moderate their pain, titrating the transition from one to the other with short term, fast acting opioids.
 - Joint working between hospital and substance use services re prescribing medication to people with PSU.
 - Taking specialist consultants to home visits to talk to district nurses about whether different doses of pain relief are warranted and appropriate. Each case needs to be assessed on an individual basis, but some people with PSU may have a higher tolerance for opioids and prescribers will need to consider this when dosing analgesics.
 - Working with homelessness professionals, hostels and substance use services to maximise the support they can offer and to try to keep people safer than on the street.
 - Good GP prescribing of methadone at appropriate dose levels – need to work to develop relationships with individual GPs and consultants.

Practice examples

- Pallaborative, a PC/EoLC network set up in Liverpool, develops local level guidance on specific issues of concern across the sector regionally. This has recently included substance use.
- A multi-disciplinary network in Liverpool has been set up between relevant colleagues from across substance use, PC, EoLC, GP, City Council and other relevant agencies, to focus on a collective response to PC and EoLC for people with PSU.

Professionals advise:

1. Get consent to share information to avoid the person having to repeat the same information frequently.
2. Share information on a person’s care needs with GPs, and be prepared to advocate for them, particularly around palliative care registration. GP’s use of the PC register is inconsistent and people with problematic substance use may not be considered adequately for inclusion.



3. Share information and be prepared to advocate for people with other services and professionals too – arrange for support to appointments where possible to offer support and advocacy. Vital to this process is the need to communicate well to understand what each service is doing and to understand the role and remit of the other professionals involved in someone's care.
4. It is important to see interventions for PSU and palliation in tandem: it is not an 'either/or' choice.
5. Acute or social care professionals could consider whether referrals are needed to both addictions team and PC/EoLC services.
6. Work together on what advance care planning might look like for someone at end of life with problematic substance use.
7. Discuss with practice partners who is taking responsibility for the oversight of the person's care otherwise the person might fall between the gaps in services. Don't allow this discussion to become an obstacle to appropriate and empathic care.

3. Talking about substance use and end of life care

“We’re already happy to talk about death and dying and your plans and how you might die...we can talk about that all day long and not be upset about raising those questions with patients, but yet I’d probably have palpitations ...asking, ‘Have you been injecting heroin again or what have you been drinking?’

*(Group 2 – Senior HSCP)
(Templeton et al. 2018: 34)*



Social and health care professionals are experts at asking people for all sorts of personal information. Professionals are confident in the questions they ask routinely, but less so when it is something they are not familiar with. Evidence suggests that people want to know more about what and how to ask someone about their substance use or their wishes and needs as they approach the end of their lives.

- Remember, words only make up a small proportion of communication – tone of voice, facial expressions, eye contact and other non-verbal communication are important
- Direct questions can be asked sensitively. Remember, too, that there may be literacy problems so paper-based or self-completion forms may not be appropriate.
- It is also important to understand that problematic substance use fluctuates along with the impact of it so what might feel (or be) life threatening one week may not appear, or be, so the week after.

- The more information you have on the different roles of people in PC/EoLC and substance use services the easier it will be to seek support and advice – and the easier it will be to explain to people approaching the end of their life about how they may benefit from a referral.
- People with PSU will normally have a range of needs, including poor mental health and possible cognitive impairment. Talking to colleagues in mental health services about how to identify and assess mental health needs and cognitive impairment at a preliminary or ‘triage’ level is advisable.

Definitions

- Establish what is meant by palliative, end of life, and problematic substance use within your agency. However, when working with others, clarify what their definitions are so you’re not talking at cross purposes. Definitions can vary hugely between agencies and the public can have a different perception too.
- Avoid a narrow interpretation of end of life: the Prognostic Indicator Guide (PIG) is a good place to start – <https://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf>
- The language of substance use can be complicated. Use of the terms ‘misuse’, ‘abuse’, ‘dependency’, are used interchangeably and sometimes mean any use, problematic or not! ‘Substance’ is often taken to mean illicit drugs rather than any substance including alcohol.
- The use of different terms also come from different perspectives and views on the nature of substance use or problematic substance use. People with PSU may feel very stigmatised and defensive, avoid using terminology or assumptions about them that risk exacerbating any shame they may feel.

- Start by differentiating between any use of substances (including alcohol and prescribed drugs), and the problematic use of substances in terms of considering responses and interventions.
- Sometimes clear definitions and prognoses are hard. Understand that a number of life limiting conditions are unpredictable.

Questions to ask about substance use

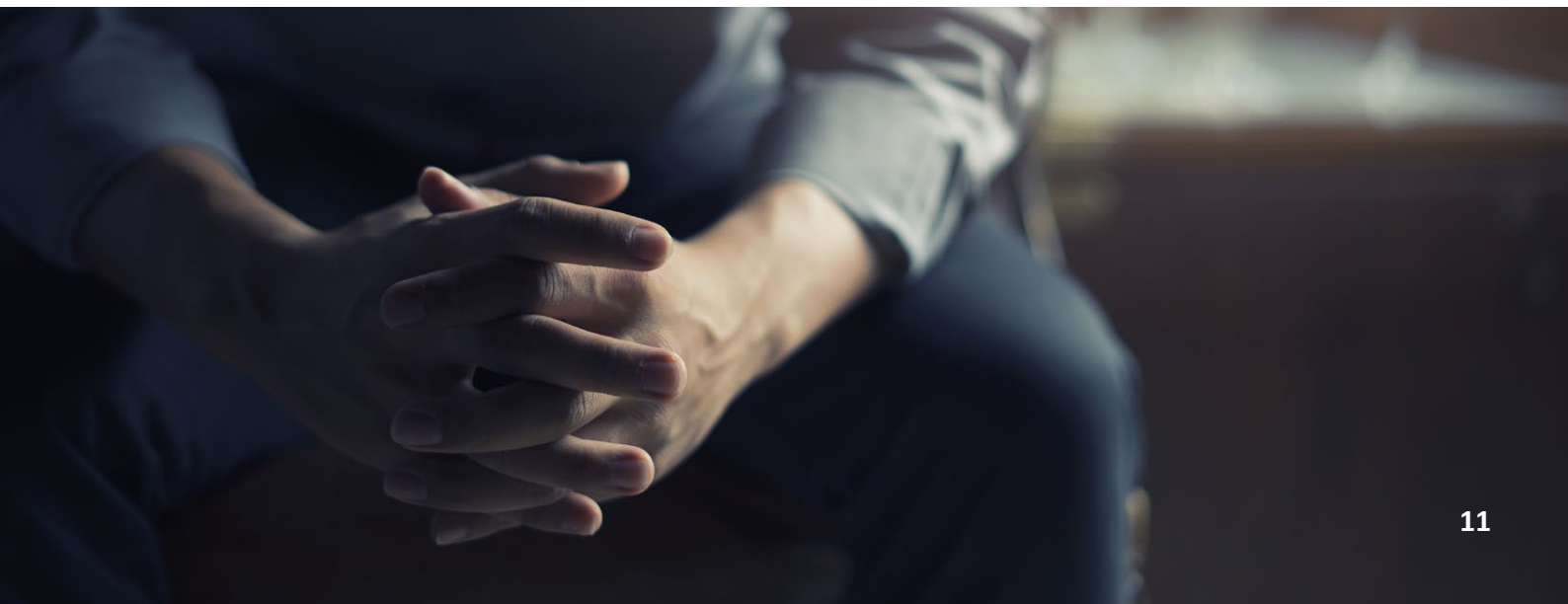
Finding the best approach to asking questions about substance use starts with clarity about why you're asking and what your value base is. The following quote comes from a hospice professional who is not judging the person for their alcohol problems in the final period of their life but is also wanting to offer the person a choice and support around their drinking if they want it:

"Let them know that we do not want to take you away from this situation at this moment in time, we don't want you to stop drinking, we don't want you to stop living your life how you have always lived it. What we want to do is support you."

*(Group 1 – Frontline HSCP)
(Templeton et al. 2018: 39/40)*

Examples:

- Can you tell me about your alcohol and other drug use right now and how that is helping you at this time?
- What would you like to do in relation to your substance use and how can we help?
- We will not judge you for your substance use, we just need to make sure we can give you the right medications and care – we don't want to make things worse for you.
- I am not suggesting you stop using or drinking if that's what you want to do, but knowing a little about what you are using will help us to keep you safe medically.
- To what extent would you like to change anything about your drinking/using at this time?
- Is there anyone around you we should know about that can support you in making the changes you want to make to your substance use? What has helped you previously?
- Are there people we should know about who you might want to avoid, to help you make the changes you want to make in relation to your substance use?



Questions to ask about people's needs and wishes for end of life care

Some people will not want to stop their substance use. However, they still need to be offered advice and choices, where available, about their options for palliative and end of life care. One frontline professional found that, in such circumstances, it was helpful to set aside discussion about the substance use and proceed with discussion about palliative and end of life care.

“Right, let’s assume that you’re not going to stop drinking, then let’s look at that and then I can refer you to the hospice, I can refer you to a counsellor, I can refer you to other things’, like you and I would access (Group 1 – Frontline HSCP)”

(Templeton et al. 2018: 39/40)

- You need to be able to talk about death with someone particularly if you’re already talking to them about long-term conditions and multiple medical needs. People may drop cues into conversation to see if you will pick up on them as they may not know how to raise the topic. It is important not to miss those opportunities and to listen carefully for cues.
- It can be difficult to use the terms ‘end of life’ with people. Sometimes asking open questions can help the patient to then direct the conversation:
 - How do you feel things have been with your health recently? Have you had any concerns about this? Questions about the future can also be helpful.
- Not everyone will want to talk about their death or dying so make a professional judgement based on initial sensitive enquiries about end of life care. For some people, it might be a question of picking the right time. It might be appropriate to gently introduce the idea after a ‘close call’ with serious illness/death. Perhaps frame it in terms of:

- Your recent illness made me realise that we should have a conversation about what your wishes are if you become ill like that again. Who would you want me to contact? Where do you want to be cared for? What do we need to think about to plan for your future care?
- Alternatively: Perhaps if we write your next recovery plan to include some things that will help you stay well and do the things that are important to you , but also put in some mention of what you would want if you become very poorly again... .
- Reassure people with PSU that their end of life will be made as comfortable as possible and prescribing will take account of their other drug use.
- The Serious Illness Care Programme is being piloted in the UK with guidance on how to have conversations about serious illness – initially it is targeted at “doctor and patient”. Progress and future resources can be followed online at: <http://betterconversations.org.uk/about/>

Further examples:

- What do you want your end of life to look like? Is there anything that you’d like to change?
- How can we improve your end of life experience? How can we make it what you want it to be?
- Would you like to be supported to continue drinking or using when you are at the end of life?
- What are your fears or concerns about your substance use towards the end of life?

Substance use screening and assessment tools

There is limited evidence of the efficacy of substance use screening tools within a palliative or end of life care population. However, the evidence suggests that screening and ongoing assessment is important as people’s use may change and this will need considering in relation to their care planning.

As a starting point, something more conversational as suggested above is likely to be less intimidating than a formal assessment tool, particularly for people at or near the end of their lives. Above all, the most important consideration is how any screening tool is used – it needs to be introduced in a way that ensures the individual being screened feels compassionate understanding.

The following tools can be used but it is also worth contacting your local alcohol and drug services and asking them to suggest screening questions for you.

Universal screening tools for alcohol use

- The UK Government website provides a link to a number of alcohol screening tools and can be accessed online here: <https://www.gov.uk/government/publications/alcohol-use-screening-tests>. This includes the AUDIT, commonly considered one of the best alcohol assessment tools available and validated with different groups of people with different co-existing needs.
- There are also a number of screening tools used with older people including The MAST- G (Michigan Alcohol Screening Test – Geriatric) is a specific screening tool for assessing alcohol use in the elderly. MAST – <http://www.the-alcoholism-guide.org/michigan-alcohol-screening-test.html> There is also a short version of the tool (called the SMAST-G) which may be useful. <http://sbirt.vermont.gov/screening-forms/older-adult-alcohol-screening-instrument/>
- The British Liver Trust provides a range of information for practitioners and clients about the liver, including where there are liver problems because of alcohol use. <https://www.britishlivertrust.org.uk>
- The Royal College of Psychiatrists (2015) has produced an information guide on Substance misuse in older people. <https://rcpsych.ac.uk>

Universal screening tools for illicit drug use

- There are few agreed and validated tools for assessing substance use other than alcohol. One short screening tool is the DAST – Drug Abuse Screening Tool. <http://www.emcdda.europa.eu/html.cfm/index3618EN.html>
- The clinical Opiate Withdrawal Scale (COWS) may be useful to measure any withdrawal symptoms from opiates – <https://www.drugabuse.gov/sites/default/files/files/ClinicalOpiateWithdrawalScale.pdf>
- Other tools are available for different groups of people or substances of choice. <https://smartcjs.org.uk/professionals/gps/screening-tools/>

Additional guidance suggests:

- Observe for behaviours associated with problematic substance use (requests for dose escalation, A&E visits, unscheduled clinic visits related to pain complaints, seeking early prescriptions, lost opioid prescriptions, approaching different prescribers, forged prescriptions).
- There is a need for non-judgemental curiosity when such presentations occur – not automatically assuming that an individual is drug seeking, but exploring whether they perhaps have poor coping strategies, are feeling scared, or are in pain.
- Equally you may notice behaviours, such as using more drugs than have been prescribed, looking for intoxication. Exploring the reasons behind behaviour will support teams to provide the best care. It can also trigger conversations about EoLC and future planning, or, if those have already taken place, ensure individuals continue with EoL/palliative care. Don't waste opportunities.
- Assess and proactively treat alcohol or drug withdrawal at the end of life.
- Check whether people can actually get to appointments – physically and financially.

4. Pain and symptom management and prescribing

“I guess where we hear about things that are of concern clinically, [it] will be things like people being afraid to prescribe analgesia properly, particularly if somebody has a heroin or some kind of a drug related abuse...my clinical experience is that some people, particularly with heroin abuse or related drugs, have a very high tolerance for the drug and therefore they need really big doses...people are really afraid of really big doses and so I think that there is a tendency to underserve this population.”

(Group 3 – Policy & Commissioning Professionals) (Templeton et al. 2018: 51)

The primary challenge identified in the evidence for health professionals in particular, was the difficulty they faced around appropriate pain and symptom management and prescribing practice for people with current or historic problematic substance use.

Prescribing pain medication for people with problematic substance use at, or near, the end of their life is complex but good practice is achievable. Much of the existing literature is based on anecdotal evidence rather than strong empirical data. There is evidence of under prescribing for pain because of concerns about overdose and professional culpability. Some literature refers to ‘pseudo-addiction’ where illicit substances are sought to supplement under prescribing of pain medication. Screening, effective supervision and close monitoring of prescribing can overcome most of these concerns.

Assessment considerations

- Assessment before and after prescribing medication is an important step to manage pain effectively. Health professionals need to distinguish between active users, individuals in methadone replacement therapy, and those in recovery. This often needs comprehensive, expert negotiations that may require inter-disciplinary communication with drug, alcohol, and psychiatric services.
- Assessment of the attitude and perceptions of opioid use from the person with problematic substance use at the end of life is also crucial. If that person is in recovery they may be reluctant to take opioid-based medication. This is generated from the fear of the addiction/withdrawal and the historic problems those substances caused in the person’s life.
- Alternatively, the person may be concerned with stigma and believe there would be a withdrawal of care and opioid medication if they were open and honest about their illicit drug or alcohol use.
- Discuss drug use and its impact and the importance of being open with health staff so that they can ensure pain and other symptoms are managed. This should include situations where the person reduces or stops their illicit drug use or alcohol use.
- Conduct frequent pain assessments and reviews of symptom distress. This is likely to be required more frequently than ‘normal’.
- Implement safety plans for identified patients with substance problems or high risk patients. Involve and/or refer to specialist Multi-disciplinary Team (MDT) support that may include psychiatric/ psychological, or drug and alcohol services. This may include supervised medicines administration by health professionals.

- During follow-up visits use tools such as the Pain Assessment and Documentation Tool (PADT) to assess levels of analgesia, the effect on capacity to self-care, and any adverse reactions. <https://www.quest.scot.nhs.uk/hc/en-gb/articles/115004244089-Pain-Assessment-and-Documentation-Tool>
- Set realistic goals related to pain management at the end of life that are based on harm reduction rather than abstinence goals.
- Look out for similar symptoms that can be easily misdiagnosed, e.g. sudden withdrawal from substances vs peritonitis.
- Assess for withdrawal symptoms resulting from physical deterioration and inability to physically access substances including illicit drugs, tobacco and alcohol – medicate or facilitate use (where appropriate).

Prescribing practice

- Reassure people that their pain will be managed in the same way that other people's pain is managed. This will help to allay fears and avoid minimising or hiding their substance use.
- Clear and honest communication is required with the person with problematic substance misuse to encourage them to disclose the type and volume of substances in order to help professionals evaluate any potential interaction with prescribed medication. This pharmacological complexity may require specialist pharmacist involvement and would need to be underpinned by a person-centred approach to patient care.
- Understand people may have a high tolerance to opiate based painkillers if they have histories of problematic substance use and adapt prescribing practice accordingly.
- Clinicians need expertise and confidence to manage pain requiring higher opioid titration that may exceed standard prescribing protocols for end of life care. This relates to other symptom management medication that could have been misused previously and is, as a result, required at a higher dose, for example, to treat anxiety. Collaboration and training with drug and alcohol services may increase this confidence.
- Levels of prescribing may need to be higher because of tolerance from historic drug use – it might not be appropriate to prescribe to levels advised in clinical guidelines. Every case should be assessed on an individual basis because although these can be issues, it should not be assumed that they are.
- Arrange for supervised consumption of alcohol and other drugs in the community as well as in care services that take account of the (changing) physical capacity of each individual.
- In terms of safety in managing pain at the end of life in the presence of substance misuse, more frequent outpatient appointments, the use of slow release pain medication with limited supply of breakthrough opioids (that can be monitored) may be beneficial.
- There may be issues to do with prescribing and substance use that need considering. For example: being maintained on methadone, being placed in a wet hostel, people with opiate use histories not wanting to be prescribed opioids, or services that have a zero tolerance substance use policy. These need to be considered as part of the prescribing process and follow up.
- Clear inter-disciplinary communication is vital to assess the potential risk of poly-prescribing and poly-pharmacy, with potentially multiple prescribers working with people with substance use problems (for example, A & E departments, psychiatric or drug and alcohol services).
- If people become physically unable to smoke, drink or use drugs independently, they will experience the negative impact of withdrawal symptoms. Professionals need to be aware of this to prescribe additional drugs to maximise their comfort during that time.
- While there is currently no guidance for this group of people specifically, NICE guidance on prescribing strong opioids in palliative care is available at: <https://www.nice.org.uk/guidance/cg140/resources/palliative-care-for-adults-strong-opioids-for-pain-relief-pdf-35109564116677>

Monitoring

- Discuss with the person how, and whether, they will be able to keep their prescribed drugs safe in the home.
- Some examples of what could be considered include the use of safes, lock boxes, daily deliveries, or next of kin looking after medication.
- Pill counting may be a way to assess for drug diversion and the use of non-opioid adjuvant medications may be preferable whenever possible, in order to maintain safety and reduce risk.
- Don't assume people have ulterior motives for wanting pain medication – discuss concerns and plan with the individual and family/friends (if appropriate).
- If it becomes clear at some point that people do have ulterior motives for wanting pain medication, consider why that might be and how you can support them to do things differently. It may be a way they have used to cope with high stress situations for example. Be curious, rather than judgemental, about what such behaviour might mean and what insight this can offer you in terms of offering support.
- For people with PSU who are homeless, it may be a shelter worker or a friend at a hostel who is closest to the person and could potentially assist with medication dispensing and monitoring. But this requires proactive engagement and relationship building from health and social care staff to facilitate this.



5. Support for staff

“this is not how they want[ed] their life to be, not the script that they wrote for themselves, it’s just where they are...”
(Substance Use professional)

(Galvani et al., 2018)

The complex needs of people with PSU needing palliative or end of life care can add stress and strain on frontline practitioners, however experienced they are. They are not immune to the sadness and loss when someone they are working with dies, nor to the frustration and emotions that accompany working with someone who does not want to change their problematic substance use.

Evidence from Galvani et al. (2018) suggests it is important to acknowledge and provide emotional support for staff as well as training opportunities to help them work more confidently with this potentially growing group of people and their families. What professionals found helpful and supportive was:

- Pairing practitioners with volunteers to facilitate close working and mutual support.
- Working in pairs of practitioners where perceived risks were identified relating to substance use, paraphernalia and drug dealing environments.
- Having a team approach, rather than an individual approach to care. This was very helpful in developing care provision and supported decision-making – particularly MDT. It helped to overcome the fear of getting it wrong – a fear for patients and for their professional status.
- Having regular supervision (internal and/or external) around loss and bereavement for staff.
- Emotionally responsive teams were valued, as were managers who balanced the administration requirements with the emotional support needs of staff, and colleagues who supported each other.

- For substance use professionals, a team based approach to anticipating death and loss among people was helpful. Talking about death and loss more regularly with colleagues helped it to become a more normal part of their role.
- Understanding what a ‘good death’ would be for each person.
- Existing guidance on managing multiple, long term conditions could be adapted for responding to this group of people (Goodwin et al. 2010).

A large number of topics for further training were found in the evidence base. There was some evidence that professionals lacked confidence in asking about the ‘other’ topic (either substance use or end of life) and that some mileage might be made in reminding them that they are already skilled communicators in one field of knowledge and that such skills are transferable in relation to dealing with uncertainty, sensitive issues, family members.

However, there were some common themes for training that crossed both substance use and palliative/end of life care professional groups:

- Pain management for people with PSU
- Working with specialists from the ‘other’ area
- What a care pathway might look like between substance use services and Palliative/EoL care
- The need to develop specialist training partnerships between hospices and substance use agencies
- Having a specialist or lead in EoLC/Substance Use on team or easily accessible as a key point of contact

Training is important to ensure a consistent agency response to the needs of people with PSU at or near the end of their lives. Training and resource requests are listed below to help the development of local training exchanges and planning:

| Substance use professionals | Palliative and end of life care professionals |
|--|---|
| <ul style="list-style-type: none"> • Training pack on working with people with life-shortening conditions in substance use services | <ul style="list-style-type: none"> • Identification and asking questions about substance use; how to talk about it |
| <ul style="list-style-type: none"> • Identification and asking questions about physical health conditions and diagnoses | <ul style="list-style-type: none"> • Management of medication where there is substance use |
| <ul style="list-style-type: none"> • Planning and talking about EoLC | <ul style="list-style-type: none"> • Staff need for psychological support – additional stress of hearing people’s past lives |
| <ul style="list-style-type: none"> • How to deal with bereavement – avoiding ‘we know how you feel’ | <ul style="list-style-type: none"> • Impact of substance(s) on physical and mental health |
| <ul style="list-style-type: none"> • Types of palliative and EoLC intervention available | <ul style="list-style-type: none"> • Types of substance use treatment available |
| <ul style="list-style-type: none"> • Emotional responses to end of life care | <ul style="list-style-type: none"> • Effective communication training before the implementation of screening/assessment tools |
| <ul style="list-style-type: none"> • Identifying life shortening illness and range of conditions | <ul style="list-style-type: none"> • Identifying problematic alcohol and drug use |
| <ul style="list-style-type: none"> • Impact of EoLC on family and supporting families through EoL and bereavement | <ul style="list-style-type: none"> • Impact of PSU on children, families and parenting and supporting them through palliative/EoLC |
| <ul style="list-style-type: none"> • Assess risk relating to end of life | <ul style="list-style-type: none"> • Drugs and their effects |
| <ul style="list-style-type: none"> • Attitudes and values re EoLC | |
| <ul style="list-style-type: none"> • Ethnicity, culture and EoLC | |
| <ul style="list-style-type: none"> • Gender differences in EoLC | |

6. Family, friends and care givers

Professionals describe how:

- Families of people with substance problems can be isolated from sources of support. This includes at their relative's end of life when they are in need of support in their own right, but may be unable to talk to non-professionals about it through fear of stigma, shame, embarrassment, self-blame.
- Family members may need specialist bereavement support after their relative's death as many feel that they are 'unentitled' or less deserving of support than other families because their dead relative 'brought it on themselves' or because their relationship had been problematic and/or confrontational.
- As a result, they can feel out of place in generic bereavement groups, where bereaved family members with less conflicted relationships with their deceased relatives struggle to understand their pain and distress.
- Families may not want substance use recording on their relative's death certificate.

Service models for supporting families and carers of people with PSU and in need of PC/EoLC

- Families described good practice by health and social care professionals in terms of openly empathetic, compassionate and holistic care. They felt comfortable talking with a non-judgemental professional who recognised the strain they were under and would respond to help ease the situation for them and their dying relative.



Key messages for practitioners to share with families, friends and caregivers:

- Grief is always difficult to come to terms with and we can often feel we are facing it alone.
- Due to their substance use, we may have had a difficult relationship with our relative while they were alive and this will inevitably have made caring for them more challenging and our bereavement more painful.
- Our relative's life may have been unhappy or painful, and our memories of life with them may be distressing. Our relative may have had mental health problems and their behaviour may have caused huge disruptions within the family. We may find it particularly difficult to look at photographs and try to remember good times.
- We may feel shame at having had a relative who used substances problematically and a sense of powerlessness at not having been able to change their behaviour. We may feel guilty that our own substance use added to their difficulties in reducing/controlling their use.
- We may feel guilt that somehow we could or should have done things differently to make their life more bearable, or even that it was perhaps our fault that they used substances like they did.
- Some of us will have been estranged from our relative at the time of their death and may regret not having been able to repair relationships, or feel guilt at not caring for them more practically.
- We may have felt abandoned by the professional services and know that more could have been done to prevent this tragedy from happening.
- We may have fears about the impact of our own substance use upon our health, or over our children perhaps experiencing substance use problems and mental health difficulties in the future.

Services need to:

- Assess what family support there is available for people in their own right.
- Discuss safe medication management with them if appropriate.
- Assess (sensitively) family members' and significant others' risk of potential drug diversion – ensuring that perceptions of 'risk' are proportionate and not solely informed by negative stereotypes of people with substance problems.
- Recognise that family members can be viewed negatively by some staff and volunteers, particularly if they have their own substance problems or behave in an uncooperative or 'chaotic' way. Training about the support needs of families of people with substance problems and how best to address those needs may be required.
- Be aware that some families will have experienced poor responses from health and social care practitioners – either for themselves and/or their relative – as a result of the substance use label.
- Recognise and respond to the range of roles of family, friends and care givers – some may be using substances, some may be supportive, some may be estranged, they may be attempting reconciliation, may be abusive, may be angry and grieving, etc.
- Consider providing volunteers to support family members during and after death of their relative – this can be particularly effective where those volunteers have personal experience of having had a substance problem or of having cared for someone with a substance problem.
- Encourage and support people to access bereavement support groups or counselling – including specialist services, if possible.



Resources

End of life care for people with problematic substance use

Research Briefings, Full Reports, and other resources from Manchester Metropolitan University's research on end of life care for people with problematic substance use. Available at: <https://endoflifecaresubstanceuse.com/>

- To be added to the Community of Practice network set up at ManMet, please contact Dr Sam Wright on sam.wright@mmu.ac.uk

Tools and information

Adfam

Adfam is the national organisation working with and for families affected by drugs and alcohol. <https://www.adfam.org.uk>

Al-Anon Family Groups

This fellowship, based on 12 step models of peer support, offer support to families affected by a relative's problem drinking. <http://www.al-anonuk.org.uk/>

Amber Care Bundle

A communication and planning tool for clinical teams to proactively manage the care of hospital patients who are facing an uncertain recovery and who are at risk of dying despite treatment. "Uncertain recovery" is taken to mean that a patient is being actively treated for an acute problem but may not recover, due to limited reversibility caused by an underlying illness. <https://www.ambercarebundle.org/homepage.aspx> [Accessed 26/03/19]

See also: Guy's and St Thomas' NHS Foundation Trust 2015 *The AMBER care bundle – a guide for patients, their relatives and carers*. <https://www.ambercarebundle.org/documents/amber-care-bundle-a-guide-for-patients-their-relatives-and-carer.pdf> [Accessed 26/03/19]

Cruse

Cruse supports people who have been bereaved due to the death of someone close. <http://www.cruse.org.uk/>

DrugFAM

DrugFAM provides support to families, friends and carers who are struggling to cope with a loved one's addiction to drugs or alcohol. <https://www.drugfam.co.uk/>

Dying Matters

Dying Matters aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life. Among a range of services, it offers *Find Me Help* which is the UK's most comprehensive directory of services for people in the last years of life, their families, carers and friends – <https://www.dyingmatters.org> [Accessed 26/03/19]

Macmillan Cancer Support

Macmillan provides practical, medical and financial support and end of life care and pushes for better cancer care. <http://www.macmillan.org.uk/information-and-support/coping/at-the-end-of-life>

Marie Curie

Marie Curie offer a range of resources and support through terminal illness. <https://www.mariecurie.org.uk/>

National Council for Palliative Care

NCPC is an umbrella charity for organisations in the UK working with people in palliative or end of life care. <https://www.ncpc.org.uk/> [Accessed 26/03/19]

Pallaborative network

A collaboration of health care professionals working in specialist palliative care, patients and members of the public from across the North West of England, working to improve the quality of care for people with advanced progressive disease and to ensure care is based on the best and most up to date evidence possible. The website contains a range of clinical audit, guideline development and education materials, useful for all health care professionals who care for people with advanced, progressive disease. The clinical standards and guidelines for palliative and end of life care are developed using a robust process and are NICE accredited. <https://pallaborative.org.uk/>

The Royal College of Anaesthetists (RCoA)

The UK professional body responsible for the quality of patient care through the maintenance of standards in anaesthesia, critical care and pain medicine – provides a lot of useful information about opioid use and pain management: <https://www.rcoa.ac.uk/faculty-of-pain-medicine/opioids-aware/opioids-and-addiction>

The Serious Illness Care Program study (and conversation guide).

(Ariadne Labs 2016) <https://www.ariadnelabs.org/wp-content/uploads/sites/2/2019/03/SI-DFCI-Outcomes-fact-sheet-2019-03-12c.pdf> [Accessed 26/03/19]

SMART Recovery Family and Friends Programme

SMART UK offers group based support to those affected by another's substance use. <https://www.smartrecovery.org.uk/family-friends/>

The Supportive and Palliative Indicators Care Tool (SPICT).

Devised by the University of Edinburgh (Updated) (2018) www.spict.org.uk [Accessed 26/03/19]

Useful reports and articles

Action on Addiction (2013) *The management of pain in people with a past or current history of addiction*. Available online at: https://idhdp.com/mediaimport/38281/130607_pain_management_report_final_embargoed_13_june.pdf [Accessed 27/03/19]

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British Pain Society (in collaboration with The Royal College of Psychiatrists, The Royal College of General Practitioners and The Advisory Council on the Misuse of Drugs) (2007) *Pain and substance misuse; improving the patient experience*. London, The British Pain Society. https://www.britishpainsociety.org/static/uploads/resources/misuse_0307_v13_FINAL.pdf [Accessed 26/03/19]

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Clinical Guidelines on Drug Misuse and Dependence Update Independent Expert Working Group (2017). *Drug misuse and dependence: UK guidelines on clinical management*. London, Department of Health <https://www.gov.uk/government/publications/drug-misuse-and-dependence-uk-guidelines-on-clinical-management>

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See also: Gold SF Prognostic Indicator Guide (PIG) <https://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf>

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NICE (2012) *Palliative care for adults: strong opioids for pain relief*. NICE. [nice.org.uk/guidance/cg140](https://www.nice.org.uk/guidance/cg140) <https://www.nice.org.uk/guidance/cg140/resources/palliative-care-for-adults-strong-opioids-for-pain-relief-pdf-35109564116677> [Accessed 26/03/19]

Walshe, C.E., Dodd, S.R., Hill, M., Ockenden, N., Perez Algorta, G.D., Payne, S.A. and Preston, N.J. (2016) 'ELSA: a randomised wait-list controlled trial and embedded qualitative case study evaluation assessing the causal impact of social action services on end of life experience.' *Palliative Medicine*. 30, NP1-NP401. <https://doi.org/10.1177/0269216316646056> Lancaster,

Lancaster End of Life Observatory. <https://www.lancaster.ac.uk/health-and-medicine/research/ioelc/ioelc-publications/#d.en.401078> [Accessed 26/03/19]

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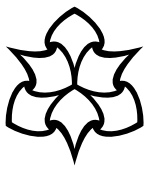
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